"It's your right - but do you really want to know?"

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I would like to say at the outset, and it was emphasised to me listening to Yvonne's comments, that I believe that this is an extremely important area which is not discussed enough. Yvonne's comments have highlighted the very genuine dilemma health professionals are facing now and will face increasingly in the future when they possess information that might affect another person, but where the disclosure of that information has the potential to cause psychological distress. Obviously there are many instances, such as genetic information or risk of infection, where health information is going to come into the possession of health professionals and a decision has to be made what to do with it.

Should we tell?

I thought I would turn the question around and rather than ask "Do you want to know?", ask the question, "Should we tell?". This is not an easy question to ask in the current environment, where there is so much emphasis on patient autonomy, provision of information to patients and access to patients' records.

The prevailing philosophy is very much one of having a duty to give the patient access to this information. The range of issues Yvonne has talked about highlights the need, in some circumstances, to question that assumption. More information is not always better than less. We need to think very carefully about the circumstances in which we might want to tailor the information we give. Equally, on the other side, any inroads we make into the principle of patient autonomy and disclosure of information have to be very carefully argued through and justified.

I am going to talk a little about some of the legal principles that might apply, but which are, in my view, not particularly helpful. But they are all we have at the moment to deal with, when analysing the legal framework in which we are making these decisions. I will discuss what the effect of those principles might be and then conclude with some suggestions about how we could better formulate a policy to decide what exactly we should be doing when such information comes into our hands.

The current legal background

First of all, looking at the legal principles, a good place to start is the High Court decision of *Rogers v Whitaker*. If a doctor is asking a patient to consent to medical treatment, there is an obligation to disclose to the patient all risks relevant to the patient's decision about whether or not to undertake that treatment. That is now relatively uncontroversial. There would be a lot of controversy, amongst those in this room, about whether or not *Rogers v Whitaker* has gone too far in obliging a doctor to disclose more than ought to be disclosed, but I don't want to touch on that aspect. That could be a subject for another meeting. But, certainly, the principle is that, if you are asking a patient to agree with something, you have got to put the patient in a position to make an informed decision.

We have to be careful not to try to carry *Rogers v Whitaker* too far when we are looking at a different question: not what did the patient need to know in order to make a decision about medical treatment, but should we always oblige patients to know every bit of health information we have about them, particularly in circumstances where they might not even know that we have the information? It might not be in their best interests; they might not be

able to do anything useful about it. So although *Rogers v Whitaker* certainly informs the environment in which these decisions are being made, it doesn't actually say much that is helpful from a legal point of view to assist us in making these decisions.

That same environment, emphasising obligations of disclosure and transparency and openness, is further reinforced by current privacy legislation, and of course there is now a right of patient access to records. Again, that is a slightly different question. If a patient asks for the information, the privacy legislation, subject to a few exceptions, would say that you have to give it to them; but again, that doesn't tell us much about whether you have to hunt out the patient and disclose the information where the patient isn't actively asking for it.

The doctor's legal duty

So what really is the legal duty owed in these circumstances and how would the courts define it? There is not a great deal of particularly informative case law on this question. There is, of course, the American case of *Tarasoff*, on duty to warn, which has never really received much recognition in Australia, and so will not carry us very far. We are really left to go back to first principles and ask, "Does a duty of care exist in the circumstances, looking at the issues of proximity and forseeability and so forth?".

I want to give you just one example to try to demonstrate how problematic this is and how you cannot automatically assume that there would be a duty to disclose. It is an example familiar to those of you who have served on ethics committees. It is a not uncommon scenario to come before those committees: a clinical research protocol that involves the collection of tissue with a little add-on at the end of the protocol that says, "once we have collected this tissue and we have done all the things we want to do to it, we are going to conduct a series of genetic tests to see whether there is some pattern that might emerge to explain the disease we are looking at".

It is a bit of a fishing expedition, and I don't mean that in a pejorative sense, because it is the way a lot of medical research is done. You have a hunch and say, "well, it might be interesting just to look and see what is going to happen". Ethics committees on which I have served have approved those sorts of protocols, albeit with some misgivings about exactly what it is going to mean once the genetic information is available. But suppose that the research goes ahead and that the genetic test does reveal a particular familial disposition to a certain kind of genetic condition. Does the researcher owe a duty of care to the family members of the research participant from whom the tissue was taken to disclose the information?

There is, of course, another issue lurking here: whether or not the testing should have been done in the first place without the consent of the family members. If you put that to one side and say, "we have the consent of the research subject", what is the duty of care between the researchers and the multiple family members of that subject who may or may not be affected by the same genetic condition that you have found in the subject?

Is a duty of care owed here? I am not sure that I can come up with a definitive answer. I think that, much as Yvonne has proposed, you would hope that courts would weigh different considerations pointing in favour of either disclosure or non-disclosure. There are a number of factors you could say would be relevant. For example, how serious a condition are we talking about? What is the degree of probability or the magnitude of risk that these other people would actually be affected by it? Is the condition treatable? Is there anything useful that they can do with the information? Would knowledge of the information affect significant life decisions they might make? Would it affect decisions about child-bearing? If it is a condition that affects boys but not girls, might prospective parents wish to undergo some form of sex selection before having children.

Picking up on Yvonne's point, what harm could be caused by the disclosure? I don't think that you can assume that there is not a negative side to that. Does the condition pose a risk to others? We have multiple examples of 'look-back' programs the Red Cross has run where it has certainly been accepted that disclosure is appropriate because of the risk of the condition's being passed on.

And if you look at criteria of this kind that should be weighed when you are making those decisions, I am not sure that the examples we have had in recent history in Australia would necessarily stand up to that sort of analysis. I say that with the CJD experience particularly in mind.

Creutzfeldt-Jakob Disease

I have also served on a Government CJD advisory body — at a slightly different time and with a slightly different focus from the board on which Yvonne served. My involvement with the National Pituitary Hormones Advisory Committee was in the mid-1990s when the contact tracing was largely over, when the vast majority of hormone recipients had been located and had been told of the risk, and when an enormous government apparatus had been set up to deal with it. There was a whole section within the Commonwealth Department of Health dedicated to pituitary hormones. There was a panel of counsellors and all the hormone recipients had been offered counselling. It was a very impressive operation in many ways. It had all been set up by the time I came on the committee. We were sitting there waiting for the wave of catastrophe that didn't happen.

So my time on the committee was spent trying to hose things down, trying to wean hormone recipients off counselling because the representatives of the recipient community who were on the advisory council felt very strongly that this was not helping them and that it was just perpetuating a harmful psychological reaction.

I don't mean my next comment to be critical of the decision made back then — it is not fair to do so with hindsight. We now know that only three or four cases have actually been diagnosed. What was anticipated as possibly a very large and a very significant public health problem just didn't eventuate. So if you look back now in 2005, put your hand on your heart and ask, "Did we serve the hormone recipient community well by responding the way we did?", then my view is that the answer is probably "no". As I say, that doesn't necessarily mean that we should do it differently if we had our time over again, but I think there is certainly a reason to look at that and to ask the difficult questions and to see what lessons can be learned from it.

The HIV-positive obstetric registrar

It is interesting to compare that example with the case Yvonne mentioned of the obstetric registrar who was found to have HIV. Coincidentally, being on the board of the relevant area health service at the time, I was involved in that decision-making. We did debate whether the contact tracing of the 140 or so women should take place, and we felt, on weighing the various different factors, that this was a much easier decision. Although the risk was extremely small, the consequences of finding even one person who had contracted HIV would have been extremely serious, and not just for that person but for other people as well. So, although I don't think it was an entirely straightforward decision, I look back and think that it probably was the right decision and would probably be the right decision again today.

It is interesting to ask if it hadn't been HIV, if it had been Hepatitis C, would we have felt differently, would we have responded differently? I don't know. But I think each time you change a factor in the balance a little you have to go back and think, "Can we justify the disclosure here or are the circumstances such that the preferable course is not to tell?".

Therapeutic privilege

The notion of therapeutic privilege has to be mentioned in this context, because it deals with these sorts of issues when you are talking about consent to medical treatment. If you are looking at the available legal principles that could be invoked or modified or extended to assist in providing legal answers to these questions, then therapeutic privilege obviously comes to mind. The courts have accepted that, in a limited number of cases, the psychiatric condition of the patient is such that the doctor is justified in withholding information that would have been disclosed to a patient who didn't have a psychiatric condition and who was being asked to make the same treatment decision.

A great deal is written about therapeutic privilege, but it has a very limited practical application. It would be drawing a long bow to say that you could use the doctrine of therapeutic privilege in the cases we are talking about to say, in hindsight, that you should not disclose information because of the risk of harm. Yvonne has highlighted the speculative nature of the risk and the difficulty of predicting it. Certainly in the very limited number of cases where therapeutic privilege has been upheld, it has been on the basis of very specific psychiatric evidence about the psychiatric illness suffered by the particular patient and about the likely implications for that patient of the disclosure.

Interestingly, in the recently released review of the application of privacy legislation in the health sector, there is a discussion of the exception in the Privacy Act, which mirrors the therapeutic privilege principle, by providing that the patient's right of access to records is subject to an exception where there is a risk of serious harm to the patient from having access to that information. There has been some criticism that the exception is too limited and there has been a push by a number of doctors to say that that should be broadened and that there should be a wider range of circumstances in which it should be justifiable to withhold the information. That is also an area in which debate is evolving.

I mention therapeutic privilege for the sake of completeness, to say that we do have a precedent of sorts, but I don't think it carries us very far when working out what we should do in these circumstances.

Confidentiality

Finally, we have problems of confidentiality. If you consider a situation where disclosing the information to a third party involves breach of a duty of confidentiality owed to the patient or to the person who was tested first, then again we have a conflict of obligations that has to be resolved in some way or other.

The law has always recognised that there is an exception to the doctor's obligation of confidentiality where the breach is necessary to address a serious risk of harm to another person. But many of the cases we are talking about probably wouldn't meet that test, because they involve 'merely' a 'degree' of risk. We would probably meet the test in the case of a person with HIV where we have to let another person know that one of their sexual partners has HIV and that there is a risk that they will be infected. That is the sort of case where the law at the moment would recognise that a breach of confidentiality is justified.

But if you go back to my earlier example of genetic testing done as part of a clinical research protocol: if the test did show this particular familial disposition, do you go to the research subject, the only person with whom you have a relationship, and say, "We now know that a number of your family members may be similarly affected. Can we have your consent to disclose the information?". What do you do if the research subject says, "Well, no, sorry, I don't think so"? I don't think that the law recognises that you can breach confidentiality just when there is a 'possible' risk that someone else might be affected by the condition.

Certainly, you would need some refinement of the relevant legal principles to deal with that circumstance.

Where to now?

Let me just conclude with a few general comments about where we are and where I would like to see us going. There certainly is very little law directly on point. The various legal principles I have been talking about have been developed in different contexts. They might apply, but they might be anomalous and are not really tailored to deal with the particular dilemmas we have been talking about.

One certainly cannot say, at the moment, that the law imposes a positive legal obligation to disclose all health information to affected individuals in all circumstances. I don't think we can go that far. What we have to do is to set about defining the principles which should apply to determine when you have to disclose and when you don't have to disclose.

Just to pick up again on the list of relevant factors I was talking about earlier, I think that a court would be much more likely to find that there is a legal duty to disclose, and I believe that there is also a much stronger ethical argument in favour of disclosure, where:

- a serious medical condition is involved;
- there is a high risk that the individual is affected;
- the condition is treatable;
- there is some benefit from early detection, so that, if the person can undergo testing, there might be some benefit to them from knowing of the risk in advance;
- the disclosure could avert a risk to a third party; and
- the information might affect significant life decisions of the person concerned.

It is easy if all those factors are present, but in the sorts of cases that we have been talking about, you are going to have a mix in the balance: some will be on one side of the scales and some on the other. Certainly, the risk of psychological harm from disclosure would be a relevant consideration. I agree with Yvonne that there is a need for further scientific evidence about the psychological impact of these kinds of disclosures, to properly inform these decisions.

We do need to work on developing some principles to guide decisions in this area, we need to do it with a sense of some urgency. Doctors should not be left making decisions on an ad hoc basis once they already have the information and are faced with a dilemma which hadn't occurred to them when they were gathering the information. These are obviously the worst possible circumstance in which to make those sorts of policy decisions.

Finally, I think we have to be very mindful of the fact that, if you do get to the point of saying that the information should be disclosed, then there is a duty to do so in a way that minimises the psychological effects.